DOCUMENT RESUME

ED 277 197 EC 191 704

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TITLE The Use of Biofeedback in Treating the Self-Mutilative Behaviors of a Child with Lesch-Nyhan Syndrome: A Pilot Study.
PUB DATE [85]
NOTE 12p.
PUB TYPE Reports - Research/Technical (143)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Adolescents; *Behavior Disorders; Behavior Modification; *Biofeedback; Electronic Equipment; *Mental Retardation; *Multiple Disabilities; Self Control; Self Destructive Behavior; *Self Mutilation
IDENTIFIERS *Electromyography; *Lesch Nyhan Syndrome

ABSTRACT

The pilot study focused on the effective design of adaptive biofeedback equipment for use in the control of self-mutilating behaviors in individuals with Lesch-Nyhan syndrome, typically characterized by apasticity, mental retardation, and violent biting of the lips and fingers. Utilizing an electromyographic (EMG) monitor and a custom-designed relay connected to either a computer game or a tape player, a 15-year-old male learned to control sudden high levels of arousal-related muscular tension which were the antecedents of self-abuse. A subsequent study of the experimental treatment protocol (rather than the viability of the instrumentation) is proposed. (Author/JW)

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The Use of Biofeedback in Treating the Self-mutilative Behaviors of a Child with Lesch-Nyhan Syndrome: A Pilot Study

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Running head: Treatment of Self-mutilative Behaviors

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Abstract

This was a pilot study in the design of adaptive biofeedback equipment for use by a Lesch-Nyhan patient in the control of self-mutilating behaviors. Utilizing an EMG monitor and a custom designed relay connected to either a computer game or a tape player, the subject learned to control sudden high levels of arousal-related muscular tension which were the antecedents of self-abuse. Whereas the ongoing modification of the adaptive biofeedback system precluded control of all variables for this study, a subsequent study of the experimental treatment protocol is proposed.

Descriptor Key Words: Lesch-Nyhan syndrome; self-abuse; self-abusive behaviors; biofeedback; electromyography; spasticity.

The Use of Biofeedback in Treating the Self-mutilative Behaviors of a child with Lesch-Nyhan Syndrome: A pilot study

INTRODUCTION

Lesch-Nyhan syndrome (Lesch & Nyhan, 1964) is a relatively rare but widely recognized inborn error of purine metabolism which is found exclusively in males. In addition to hyperuricemia and it's sequelae, patients with this autosomal recessive disorder manifest a well defined neurological profile involving spacticity, choreoathetosis, and mental retardation (Nyhan, 1976). In addition, all Lesch-Nyhan patients evidence a characteristic pattern of self-mutilation (typically, violent biting of the lips and fingers), which is the most striking feature of this disorder.

Since the earliest clinical documentation of this syndrome, both physical and behavioral procedures have been adopted in a attempt to ameliorate self-injury in Lesch-Nyhan patients. In general, experimental treatment protocols have fallen into the three broad categories of restraint, chemotherapy, and behavior modification. Whereas all three types of treatment have met with limited success in some form

or another, none have yielded lasting positive results without raising associated problematic issues (Christie, Bay, Kaufman, Bakay, Borden, & Nyhan, 1982).

In a study that utilized progressive relaxation in the systematic reduction of the phobic anxieties of a 10 year-old Lesch-Nyhan patient, Bull & LaVeccio (1978) were the first to promote the patient's use of internal control to deter the antecedents of self-injurious behaviors. Similarly, the purpose of the present study was to devise instrumentation which would allow a Lesch-Nyhan patient to use biofeedback to monitor his own level of muscle tension and arousal; and which would subsequently promote self-relaxation by electronically pairing low levels of muscular tension with a contingent positive reinforcement.

METHOD

Subject

The subject for this study was a moderately retarded male of native American decent who was first diagnosed as having Lesch-Nyhan syndrome at the age of five months, and who was 15 years old at the onset of the experimental treatment. At the time of the study, regular medication consisted of Allopurinol (200 mg., bid) and Valium (10 mg.

7:00 AM and 8:00 PM, 2.5 mg. at noon); both of which were continued through the study to the present. A biofeedback approach was considered for this student after it was noted that his self-mutilating behaviors occurred only above certain levels of arousal.

Materials and procedure

A computerized biofeedback system was designed to promote self-relaxation, and thus deter the sudden high levels of muscle tension which were antecedents to self-abusive behaviors. This was accomplished by the automatic activation of reinforcing electronic devices (a radio and a computer game) only when electromyographic levels were maintained below a pre-determined threshold.

EMG levels in microvolts (RMS) constituted the dependent measure of muscular tension. Levels were monitored with a J&J M59 monitor, with input leads modified to pick up two sites simultaneously, and an output modification to allow interfacing with a computer. Initial muscular sites were the erector spinae, measured simultaneously on both sides of the spinal column. However, after the subject was fitted with a scoliosis jacket towards the conclusion of the study (thus preventing access to the back), the biceps flexor cruri were

used as secondary sites. In both instances, muscles were selected which typically went into preparatory flexion prior to self-abusive episodes, thus serving as an early warning to the subject of impending self-injury.

The audio ouput of the M59 was fed into a custom designed comparator/delay system (with adjustable activation-deactivation time constant) which controlled an electrical isolation relay. Initially, the relay was connected to a radio or tape recorder which would play until the EMG readings exceeded a pre-determined threshold setting. This phase of the study afforded the subject practice in biofeedback monitoring and self-relaxation.

In the second phase of development, the system was connected to an Apple IIe computer. Exceeding the selected EMG threshold setting in this situation would cause a paddle-activated video game to freeze until sub-threshold levels of tension were restored[1]. This effectively required the subject to develop an arousal "window"; i.e. a balance between the degree of arousal and alertness necessary to play the game and the relaxation necessary to keep the game from freezing.

It should be noted that the computer game reinforcer

was implemented three months after the onset of the study as a concurrent treatment (i.e. equal time was allowed throughout the day for the radio/tape and the computer), once it became apparent that the subject understood the objectives of biofeedback. Besides regularly scheduled periods for using either the radio or the computer game, the portable M59 was left connected throughout the school day to provide an audible cue when muscle tension levels exceeded desirable limits.

RESULTS AND DISCUSSION

Since this was a pilot study in the design (rather than the effect) of adaptive biofeedback equipment; adaptations in instrumentation, data collection, and treatment procedure were made on an ongoing basis. Consequently, it was not our intention to maintain strict control of all treatment variables, and resuts were assessed qualitatively and in retrospect after all components of the system had been brought to acceptable working order. By this point, the subject had been effectively "trained" in biofeedback, thereby invalidating a subsequent controlled study with meaningful baseline data.

As the system was being developed, EMG threshold levels

were set according to baseline muscle tension prior to each treatment session. That is, the threshold setting was established at the beginning of each day, such that the subject was able to listen to the radio or play the computer game as long as muscle tension was maintained just below the level he presented upon entering school. Post hoc inspection of this daily baseline data reveals that upon first introducing the biofeedback system--with a radio or tape recorder only as the reinforcer--threshold settings were as high as 15 uv, with mean daily readings of around 6 uv. In addition, there was a mean of approximately eight instances per day during which EMG levels exceeded the threshold setting and progressed to the onset of lip biting. At present, two years after initiating treatment, daily baseline EMG levels dictate mean threshold settings of 3 uv, with highest settings typically of 5 uv, and only one instance of progression to lip biting per week.

Having designed a system which effectively allowed our Lesch-Nyhan student to monitor and regulate muscle tesion and, consequently, decrease self-abuse through internal control; the next important step in this line of research would be to employ the system in a controlled study which

would sytematically assess the effects of the treatment (rather than the viability of the instrumentation). However, since our single Lesch-Nyhan patient served in the development of the biofeedback system, we propose that other researchers evaluate a similar treatment protocol using our established instrumentation. This would require the collection of pre-treatment electromyographic data, coupled with subsequent analyses of the differential effects of the two reinforcers and the various sites used for electrode placement. Should these analyses further validate the effectiveness of this type of biofeedback regimen for Lesch-Nyhan patients, such instrumentation may become an important clinical tool in the amelioration of self-mutilating behaviors in this very special population.

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Footnotes

[1] Since voluntary control of a paddle was not possible for our subject, a throat microphone was designed such that one second of phonation produced a relay closure, which activated an "adaptive firmware card" and in turn permitted a paddle-type interaction with the computer.